Current Developmental Disorders Reports (2018) 5:116–123
https://doi.org/10.1007/s40474-018-0140-7

AUTISM SPECTRUM (A RICHDALE AND L LAWSON, SECTION EDITOR)

Service Access to Reduce Parenting Stress in Parents of Children with Autism Spectrum Disorders

Kim Desmarais[1,2] · Erin Barker[1,2] · Jean-Philippe Gouin[2,3]

Abstract

Purpose of the Review Autism spectrum disorders (ASD) are on the rise. Research has consistently shown that parents of children with ASD experience high levels of stress that impacts their health and emotional well-being.

Recent Findings Parents of children with ASD report more stress and psychological distress than parents of children with other disabilities and typically developing children. Stressors are present throughout the child's lifespan and are exacerbated at transition points (e.g., transition from high school to adulthood). However, support services may help alleviate parental stress.

Summary Parents of children with ASD experience significant parenting stress that impacts their emotional and physical well-being, as well as their marital relationships. Research has identified possible interventions to help these parents cope. Future research should focus on evaluating the impact of policy change to allow existing systems to implement the recommendations in line with research findings.

Keywords Autism spectrum disorders · Parenting stress · Well-being · Transitions · Coping · Caregiver burden

Introduction

Consider the following example. A young man with autism spectrum disorder (ASD) graduates from high school and his previous services (e.g., school, intervention center, medical services) have been terminated because of his age. He is on waitlists for several services, but in the meantime, must remain at home full time. Being unable to afford private full-time care for her son, his mother must take a leave from work to stay at home with him. This creates financial strain on the family, who now must rely on a sole income. Three months after graduation, his mother notices that his self-stimulatory behaviors have increased, and her son has regressed in his ability to take care of his hygiene. Further, he has become more withdrawn and aggressive. The mother, worried about her son, has not been sleeping or eating well, and cries often.

This plausible scenario depicts some of the difficulties experienced by children with ASD and their families during the transition to adulthood. The increase in maladaptive behaviors and the stalled rate of skill improvement is enhanced in the context of a lack of stimulating programming as a result of service gaps. The mother is experiencing increased caregiving burden, as she must provide additional care for her child who is now home full time.

The current estimated prevalence of ASD is 1 in 68, a 30% increase since 2008 [1•]. Whether this reflects true increases in prevalence or changes in the screening and diagnostic process, the demands for ASD-related care are increasing. Four times more common in boys than girls, the prevalence is higher for non-Hispanic white children compared to non-Hispanic black, Asian, and Hispanic children [1•]. ASD is typically diagnosed in childhood and is characterized by the presence of persistent deficits in social communication and social interaction as demonstrated in multiple contexts [2]. This includes deficits in social-emotional reciprocity, nonverbal communication, and in developing and maintaining relationships with others. In addition, individuals with ASD present with restrictive and repetitive patterns of behaviors and interests. These behaviors

---

This article is part of the Topical Collection on *Autism Spectrum*

✉ Kim Desmarais
Kim.Desmarais@gmail.com

[1] Center for Research in Human Development (CRDH), Concordia University, Montreal, Canada

[2] Department of Psychology, Concordia University, 7141 Sherbrooke St. West PY-146, Montreal, QC H4B 1R6, Canada

[3] Center for Clinical Research in Health (CCRH), Concordia University, Montreal, Canada

can be manifested through stereotyped or repetitive motor movements, insistence on routine, rigidity, restricted and highly fixated topics of interest, and hyper- or hyposensitivity to sensory stimuli [2]. ASD encompasses a wide spectrum of differing levels of disability and significant impairments in different aspects of the individual's daily functioning including in the social, occupational, and academic domains [2].

Raising a child with a disability can be a significant source of family stress [3••, 4•]. Indeed, ASD appears to create the highest amounts of stress for families, as compared to other disabilities (e.g., intellectual disabilities) and typically developing children [5]. This is due in part to the specific challenges of the disorder as well as prolonged dependency on parents [6]. Research from the UK found that parents often report feeling as though they are in a permanent state of crisis and describe facing constant daily challenges [7]. To accommodate their child's needs in the short and long term, parents often have to change many aspects of their lives [8].

Adding to this burden are the difficulties in obtaining services to receive a diagnosis and then accessing specialized services to intervene with the children. As a result, parents become “case managers” and are responsible for navigating the educational, social service, and pediatric health care systems in order to access and coordinate services for their child [9]. Parents often face multiple barriers when attempting to access services for their child. These include difficulties obtaining referrals for specialists and specialized services, long waitlists, and limited services once the child reaches young adulthood [10–12]. Financial stress is a common reality for these families. When parents are unable to access public services, they may choose to pay for essential services privately to help their child. In addition to the cost of the actual therapies, such as speech and occupational therapy, parents must often reduce their work hours to be available to bring the child to therapy and to learn the interventions [9]. As a result, this leads to decreased income for the family thereby increasing financial strain and ultimately parenting stress. The purpose of the present paper is to review the recent literature on parenting stress in ASD and identify potential service access improvement that would reduce stress and supporting parental well-being across the lifespan.

Parenting Stress

Parenting stress is one of the most studied aspects within families of children with ASD. These parents experience decreased physical and mental health, poor social functioning, and lower quality of life, on average, compared with other parents [13]. Parenting stress is the experience of distress that arises from the demands associated with parenting a child [14]. Stress arises from the interactions of an individual, or family, with their immediate environment and an inability to meet the demands of that environment [15]. While stress is considered a normal part of life for all families, parents of children with ASD have been found to report significant distress as compared to families of children with other disabilities and typically developing children [16, 17]. This can be attributed to the specific symptomatology of ASD, along with a lack of appropriate support and specialized services. That being said, caring for these children also goes beyond their ASD-related problems to include difficulties related to sleep, eating, and self-care as well as other comorbid medical and psychiatric conditions [18•].

Service Access and Parenting Stress While one would think that access to services would help buffer the impact of stress and perhaps lead to a better quality of life, this does not seem to be the case [13]. Unmet service needs (both perceived and real) contribute to caregiver burden [19]. In the UK, parents reported struggling with the excessive bureaucracy related to requesting and receiving services [20]. Difficulty navigating and accessing services, coordinating and receiving care from multiple agencies and professionals, and having no centralized person or place from which to obtain information are all significant contributors of parent distress [18•, 21••]. Further, fragmented services tied with constantly having to repeat their child's history is also associated with decreased well-being [21••]. Parents have to “fight” for services, creating an adversarial relationship with service providers [18•, 20]. As such, parents feel misunderstood and isolated from the professionals they are working with. Parents perceive certain school professionals as having a limited knowledge of ASD and often feel blamed by them with regard to their child's behavior [22].

As children age, parents become more concerned about their child meeting important life milestones such as moving out and finding employment [22]. However, residential care is difficult, if not impossible, to access and becomes an important concern for parents who do not want to rely on their other children to take care of their child with ASD [23]. Overall, parents appear to be more frustrated by service level characteristics (e.g., access to care) than by practitioner level characteristics [21••].

Transitional Periods

Transitions are difficult periods for families of children with ASD, because, in general, these periods are associated with uncertainty and change in services. In the following sections, research on two specific transitional periods will be reviewed: (1) following the child's diagnosis and (2) during the transition from high school to adulthood.

The Diagnostic Process Parents are often the first to observe ASD symptoms and do so much earlier than when the child receives their diagnosis. On average, parents become concerned about their child's development between 17 and

19 months of age [24]. Parents' concerns often emerge as a result of an apparent slowing down of development, lack of progress in development, or loss of a previously acquired skill [25]. A regression is reported by parents in 10–50% of cases and involves deterioration in language (e.g., loss of words or vocalizations), nonverbal communication (e.g., loss of eye contact, pointing), or loss of pretend play skills [26, 27].

The diagnostic process can be a demanding and powerfully emotive experience for families [28]. Parents have to overcome a number of obstacles to obtain the diagnosis and are given abundant amounts of information. Having noticed their child's difficulties, parents will seek out professional help [29]. This usually signifies the parents' entry into the social service system. The period during which the child's symptomatology is explored and the diagnosis is confirmed is a difficult time for parents. Parents experience frustration prior to the confirmation of the diagnosis, and there are can be significant delays in obtaining a definitive answer [10]. One of the first steps in the process is for parents to share concerns with their child's physician. This process is long and complex, sometimes resulting in a wrong diagnosis [22]. Research has shown, however, that physicians often do not take parent concerns into account, thus delaying the next step in the process [30]. Often, multiple referrals are required before the parents can consult a specialist [10]. The waitlists to meet with an ASD diagnostician are long, and parents have to wait for extended periods of time before beginning the diagnostic process [11]. Further, when children are high functioning, families experience significantly longer delays [31]. Children are typically diagnosed around the age of 36 months for children with autism, and around 7 years of age for children with an Asperger profile [32, 33]. This is especially problematic, as early intervention programs are the most effective in teaching skills and managing behaviors, especially when started at a young age [32, 33]. Thus, these delays increase family stress and hinder the start of intervention programs for the child with ASD. Further, children who are diagnosed later may no longer have the option of early intervention services, as they will have "aged out."

Taken together, these findings highlight several important issues. As health professionals are often the first point of access, more training is required to help them identify the early symptoms of ASD in young children. Specifically, more appropriately trained psychologists, pediatricians, and other health professionals are required to help speed up diagnostic processes and service access for both pediatric and adult services. Finally, collaboration between parents and professionals is essential, as parents are often the first to notice problems and regressions in development.

Transition to Adulthood The transition from adolescence to adulthood is another important transition for parents of children with ASD. The mark of this transition is the child's graduation from high school or equivalent educational services, as well as the exit from the pediatric health care system into adult care. When children turn 18 or finish high school, families lose entitlement to many, and sometimes all, services they were currently receiving [12]. Services become limited for adults with ASD, and as a result, young adults with ASD become increasingly dependent on their families for care and support [19]. Applying to new, more age appropriate services becomes more difficult as parents are faced with long waitlists and very few opportunities for program options that will help increase their child's autonomy [34]. These services are not always specific to the child's presenting problems. That is, the services may not be geared towards individuals with ASD, and often do not take into account any other comorbid psychological and physical conditions [19]. Further, research has found that young adults with ASD but no intellectual impairment are three times less likely to have daytime activities after high school than those who have ASD with an intellectual impairment [35]. These individuals may struggle to reach their potential, especially after high school, as the developmental disability service system available to them may not accommodate the unique needs of individuals with ASD without ID [35]. Finding appropriate supports may be hindered further once a child reaches the age of majority, because parents may not be able to act on behalf of their adult child with ASD if he or she does not have an intellectual disability. In sum, the current state of services for individuals with ASD, both with and without intellectual impairments, is woefully lacking.

Maladaptive behaviors present in individuals with intellectual disabilities have been found to worsen at the termination of high school [12, 36]. Given the particularities of ASD, such as strict adherence to routine and an intolerance to change [37], it is unsurprising that we see an increase in the child's behavioral symptoms during a period fraught with change and uncertainty. Even more alarming is that while students with ASD were found to be experiencing significant improvements while in school, there were no signs of improvement on any skills post high school. This can be attributed to difficulties in finding and obtaining appropriate services or settings for young adults with ASD to use and practice their skills after leaving the educational system [12].

Taken together, parenting stress during the transition from adolescence to adulthood is increased due to lack of appropriate services, obstacles in obtaining services, and the increase in children's maladaptive behaviors that occur during this period.

Proposed Interventions to Support Parents

Though interventions and policy change will take time to implement, research has identified some interesting avenues to improve support for families of children with ASD. Recommendations from the literature fall into one of three categories: (1) individual and family interventions; (2) community interventions; and (3) service-related interventions.

Individual and Family Interventions

Within the context of this paper, individual interventions are those that promote parental well-being. It is important to note, however, that when children receive appropriate intervention, it benefits not only the child but also the parental well-being [38]. As discussed throughout this paper, parents of children with ASD are faced with many stressors over which they have little control. Changing a child's problematic behaviors is often a long and difficult process, even with appropriate intervention. Indeed, for parents of children with ASD who have more chronic behavioral issues, only using a problem-focused coping approach may not be sufficient to ensure positive parent adjustment [39]. This may be because parents' subjective well-being is predicted by their perceptions of the child's lability and negativity, more than the ASD diagnosis itself [40]. In these cases, parents' acceptance of the situation may be a more effective coping strategy [4•, 41]. Some scholars have argued that teaching parents to accept the challenges over which they have no control can be as helpful as advocating for services [42]. For example, a decrease in psychological acceptance as a result of behavioral difficulties was a strong predictor of parental mental health problems in one study, and finding benefits in a stressful situation was associated with greater marital satisfaction in both partners in another study [39, 43]. Similarly, in the first year following diagnosis, the predictors of caregiver burden and parenting stress were increased negative appraisal, increased avoidant coping strategies, and decreased problem-focused coping strategies. Better marital adjustment was predicted by changes in decreased negative appraisals, decreased stress, and increased social support [4•].

Mindfulness-based interventions, acceptance and commitment therapy (ACT), and cognitive behavior therapy (CBT) have all been found to enhance parental well-being. Mindfulness interventions teach individuals to be present in the actual moment [44]. The goal is to change the way individuals experience negative situations by teaching them to accept the sensations as they feel them [44]. Mindfulness is particularly applicable with individuals facing problems with no immediate or short-term solution, as it teaches parents to become more aware of their own emotional and physical needs, and to be more mindful in child-parent interactions [45]. This approach provides a space for parents to process how they are feeling and think about a coping strategy, instead of just reacting to the stressor [41]. Mindfulness has been found to lead to significant reductions in psychological distress among parents of children with ASD that were maintained 20 weeks post intervention [41, 45]. Mindfulness is particularly beneficial to parents, as it teaches skills that can be generalized to different stressors. Further, effects were seen even when parents did not use the skills in an intensive way, but rather worked it into their daily lives where it made sense to them [45].

ACT emphasizes accepting difficult situations and provides a clarification of the person's values and beliefs related to the stressor. Similar to the effects of mindfulness therapies, research has shown improved psychological distress for parents of children with ASD with gains observed up to 3 months post intervention [42]. CBT techniques such as cognitive restructuring and monitoring thoughts and feelings have been used in groups of parents of children with special needs [38]. These techniques have helped enhanced parental well-being, which is unsurprising given that aspects such as anxiety and depressive symptoms are amenable to CBT [38].

Given the multiple responsibilities and time constraints faced by parents of children with ASD, their ability to participate in time intensive therapies may be limited. As such, it may be more beneficial given as workshops to accommodate their hectic schedules [41, 42]. Further, if such interventions are embedded within services for individuals with ASD, it may be more feasible for service systems to offer them and parents might be more likely to attend [42, 45]. Exploring other alternative modalities for treatment such as online workshops and services might increase parent participation [45]. Further, some authors recommend using more therapist-guided exercises that can help parents cope with the stressors of parenting and offering follow-up sessions targeting skills not sufficiently covered in the workshops [42].

Improving the marital relationship and co-parenting abilities of parents is essential to promoting well-being [7, 46••, 47]. Research has recommended earlier involvement of fathers in parenting to build an alliance with mothers and to offer them increased support [7]. Further, encouraging dyadic coping strategies and increased communication between parents in the marital relationship will help maintain this alliance and support [46••, 47]. Parents should be encouraged to seek emotional and instrumental support from each other, as well as from individuals within their support network [43].

Future family planning following the child's diagnosis is highly dependent on parents adapting to the diagnosis and to their new family situation [48]. Therefore, psychoeducation about the diagnosis, prognosis, and heritability may help parents make the best decisions for their families. In addition, parents and families who do not fare well tend to have closed communication, negative appraisals for stressors and situations, and lack support from each other [46••, 49]. Therefore, family level interventions should emphasize positive appraisals of stressors, have open and honest communication with each other, and consistent parenting strategies [49]. Further, interventions teaching the family to engage in problem solving and coping strategies may lead to improved family resiliency [49].

Taken together, professionals should intervene with parents to explore current coping strategies and appraisal processes, as well as their efficacy [4•]. Further, interventions with the child or family should take into consideration attributions and beliefs of parents regarding their child's behavior, teaching them to reappraise situations in a more favorable or neutral light [40]. Finally, working on the relationships between parents and other family members is important for coping and family cohesiveness.

Community Interventions

Given the importance of social support networks for parents, interventions that emphasize creating and maintaining formal and informal support systems may beneficial for parents [3••, 4•]. Support groups, such as parent-to-parent programs, have been found to be effective in helping parents build a support network [50]. These programs pair experienced parents with parents who have a newly diagnosed child. The veteran parents provide a unique form of support, as they have experienced the difficulties of the new parent and can help them cope [50]. These social networks should be free of criticism, excessive demands, and negative interactions as these exacerbate maternal stress [51•]. This may be especially important during important transitions during the family's life (e.g., following diagnosis, transition to adulthood). For example, the program "Transitioning Together" is a multi-family 8-week intervention that provides support to families during their child's transition into adulthood [52]. Specifically, it consists of group interventions for parents and their child with ASD. The group for the parents provides psychoeduation on topics related to ASD and teaches problem solving skills, whereas the child group focuses on various social skills. This program was effective in reducing parenting stress, promoting coping strategies, and creating a positive support system [52]. This provides evidence for the need for more family-focused interventions, especially during periods of change.

Community-based interventions that include psychoeducation on ASD and its related symptoms to help end stigmatization might be helpful in reducing fear of judgment for parents. Further, creating and maintaining school-based interventions may help reduce stress in parents and families that are more disadvantaged [53•]. Rethinking existing disciplinary methods in schools may also support parents. For example, some current intervention practices in schools involve expelling children in the presence challenging behaviors [54]. While it is necessary to teach children that this behavior is unacceptable, keeping the children at home creates additional stress on parents and eliminates a much needed form of respite [54].

Service-Related Interventions

Recommendations for service-related interventions include proposed avenues for policy change. The evidence presented in this paper points to the need for family centered services, as the effects of parenting stress and behavior problems will have an impact on the family unit. For example, if a mother is stressed and is unable to cope, this can have concurrent impacts on other systems within the family unit (e.g., relationship with spouse, relationships with other children). As such, services for children with ASD should include services to the child while simultaneously offering services to other family members [55]. Though not within the scope of this paper, the impact of having a sibling with ASD should also be considered and sibling interventions created to help buffer those effects. Given that parental well-being is more influenced by system level variables, such as access to care as opposed to practitioner level characteristics (e.g., perceived responsiveness), it is imperative that system-related changes be made to help support families [21••].

Services for families should work towards offering increased and flexible respite (e.g., respite when the family requires it); teaching parents how to manage difficult behaviors and oppositional behavior; offering services throughout the lifespan; and appropriate daytime activities for adults [18•, 19, 47, 56•]. Services should strive to have a care coordinator who is responsible for coordinating care and communicating with the various professionals working with the family [57]. Professionals should have open communication and collaboration with families, as well as knowledge of their values, needs, and cultural beliefs [7, 18•, 22]. Proposed interventions should be in line with family reality and take into account any comorbid conditions [18•, 46••]. For example, professionals need to work with parents to ensure that parents have the resources and time to implement recommended interventions. There is evidence that comorbid conditions contribute significantly to caregiver distress in ASD [18•, 19]. Thus, the creation of ASD-specific services that are specialized and can target multiple conditions may help reduce burden for families [19].

Finally, increased financial support for families to use for respite, private services, or tangible support (e.g., someone to come clean the house) should be offered [47]. Such support may be especially beneficial to disadvantaged families who have difficulty accessing services. Further, additional financial support such as specialized services that are covered by the government health plans, more government care plans for families of children with disabilities, better pension packages, and better policy coverage on insurance plans may also alleviate stress from families. Flexible employment opportunities that accommodate the changing needs of families may help ease stress and financial strain [57].

Conclusion

There is a wealth of research providing evidence for the significant impact of parenting stress on the well-being of parents of children with ASD. And, while there exists numerous interventions and proposed policy changes to support families, more research is needed on the best practices that will help counter the significant impacts of stress on parents. In terms of methodology, most of the intervention research reviewed employed quasi-experimental designs that lacked comparison groups; the samples were mostly convenience samples with small sample sizes that usually only included mothers; and although some of the research presented here reflected the realities of families outside of North America (e.g., Luxembourg, UK, Jordan), most of the research was conducted in the North American context. Building from these limitations, recommended avenues for future research include using randomized controlled trials to examine the effectiveness of proposed interventions on well-being; assessing fathers' experiences and well-being; and conducting cross-cultural comparisons to determine if stressors and needs are similar across cultures.

Finally, future research on interventions would benefit from taking a systems view. For example, Ecological Systems Theory stipulates that individuals are influenced by the relational and contextual systems in which they are embedded [58]. That is, individual well-being is influenced by family relationships, which are in turn embedded within and influenced by different contexts (e.g., schools and social services). From this view, the well-being of parents of children with ASD is viewed as influenced not only by the caregiving demands associated with their child's symptoms and behaviors but also by the services and interventions available to both their children and to themselves. Future intervention research should evaluate both the impact of parental interventions on child outcomes, such as behavior problems, and vice versa. Taking a systems view will ensure that research on the best ways to successfully implement interventions into existing systems takes into account both parental and child well-being to support successful family transitions [41, 55].

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

References

Papers of particular interest, published recently, have been highlighted as:
- Of importance
•• Of major importance

1.• Christensen DL, Bilder DA, Zahorodny W, Pettygrove S, Durkin MS, Fitzgerald RT, et al. Prevalence and characteristics of autism spectrum disorder among 4-year-old children in the autism and developmental disabilities monitoring network. J Dev Behav Pediatr. 2016;37:1–8. https://doi.org/10.1097/DBP.0000000000000235. **Article provides recent statistics on the current prevalence and symptomatology of ASD.**
2. American Psychiatric Association. Diagnostic and statistical manual of mental disorders, 5th ed. Arlington, VA: American Psychiatric Publishing; 2013.
3.•• Barker ET, Mailick MR, Smith LE. Chronic parenting stress in mothers of adolescents and adults with autism: vulnerability and resilience. In: Comprehensive guide to autism. New York: Springer; 2014. **Article explains the trajectory of parenting stress and how stress contributes to eventual physical and mental distress. Points to the importance of intervention throughout the lifespan and suggests some areas for intervention.**
4.• McGrew JH, Keyes ML. Caregiver stress during the first year after diagnosis of an Autism Spectrum Disorder. Res Autism Spect Dis. 2014;8:1373–85. https://doi.org/10.1016/j.rasd.2014.07.011. **Article explains factors that might be promoting or hindering maternal adjustment in the year following their child's diagnosis.**
5. Hayes SA, Watson SL. The impact of parenting stress: a meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. J Autism Dev Disord. 2013;43:629–42. https://doi.org/10.1007/s10803-012-1604-y.
6. Seltzer MM, Greenberg JS, Floyd FJ, Pettee Y, Hong J. Life course impacts of parenting a child with a disability. Am J Ment Retard. 2001;106:265–86.
7. Mount N, Dillon G. Parents' experiences of living with an adolescent with an autism spectrum disorder. Educ Child Psychol. 2014;31:72–81.
8. Hoogsteen L, Woodgate RL. Centering autism within the family: a qualitative approach to autism and the family. J Pediatr Nurs. 2012;28:135–40. https://doi.org/10.1016/j.pedn.2012.06.002.
9. Young A, Ruble L, McGrew J. Public vs. private insurance: cost, use, accessibility, and outcomes of services for children with autism spectrum disorders. Res Autism Spect Dis. 2009;3:1023–33. https://doi.org/10.1016/j.rasd.2009.06.006.
10. Howlin P, Moore A. Diagnosis in autism a survey of over 1200 patients in the UK. Autism. 1997;1:135–62. https://doi.org/10.1177/1362361397012003.
11. Shea V, Mesibov G. Age-related issues in the assessment of autism spectrum disorders. In: Goldstein S, Naglieri J, Oznoff S, editors. Assessment of autism spectrum disorders. NY: Guilford Press; 2009.
12. Taylor JL, Seltzer MM. Changes in the autism behavioral phenotype during the transition to adulthood. J Autism Dev Disord. 2010;40:1431–46. https://doi.org/10.1007/s10803-010-1005-z.
13. Vasilopoulou E, Nisbet J. The quality of life of parents of children with autism spectrum disorder: a systematic review. Res Autism Spect Dis. 2016;23:36–49. https://doi.org/10.1016/j.rasd.2015.11.008.
14. Deater-Deckard K. Parenting stress and child adjustment: some old hypotheses and new questions. Clin Psychol-Sci Pr. 1998;5:314–32. https://doi.org/10.1111/j.1468-2850.1998.tb00152.x.
15. Folkman S, Lazarus RS. If it changes it must be a process: study of emotion and coping during three stages of a college examination. J Pers Soc Psychol. 1985;48:150. https://doi.org/10.1037/0022-3514.48.1.150.
16. Baker-Ericzén MJ, Brookman-Frazee L, Stahmer A. Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. Res Pract Persons Severe Disabl. 2005;30:194–204. https://doi.org/10.2511/rpsd.30.4.194.
17. Rao PA, Beidel DC. The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. Behav Modif. 2009;33:437–51. https://doi.org/10.1177/0145445509336427.
18.• Galpin J, Barratt P, Ashcroft E, Greathead S, Kenny L, Pellicano E. The dots just don't join up: understanding the support needs of families of children on the autism spectrum. Autism. 2017;1–14.

https://doi.org/10.1177/1362361316687989. **Article provides an interesting qualitative account from the perspective of parents with regard to helpful and less helpful professional practices in promoting well-being.**

19. Cadman T, Eklund H, Howley D, Hayward H, Clarke H, Findon J, et al. Caregiver burden as people with autism spectrum disorder and attention-deficit/hyperactivity disorder transition into adolescence and adulthood in the United Kingdom. J Am Acad Child Adolesc. 2012;51:879–88. https://doi.org/10.1016/j.jaac.2012.06.017.
20. Preece D. A matter of perspective: the experience of daily life and support of mothers, fathers and siblings living with children on the autism spectrum with high support needs. Good Autism Prac (GAP). 2014;15:81–90.
21.•• Hodgetts S, McConnell D, Zwaigenbaum L, Nicholas D. The impact of autism services on mothers' psychological wellbeing. Child Care Health Dev. 2017;43:18–30. https://doi.org/10.1111/cch.12398. **Article studies the influence of formal service on maternal well-being. Provides information about aspects that could be potential points of intervention in promoting and supporting parental well-being.**
22. DePape AM, Lindsay S. Parents' experiences of caring for a child with autism spectrum disorder. Qual Health Res. 2015;25:569–83. https://doi.org/10.1177/1049732314552455.
23. Gray DE. Ten years on: a longitudinal study of families of children with autism. J Intellect Dev Dis. 2002;27:215–22. https://doi.org/10.1080/1366825021000008639.
24. Chawarska K, Paul R, Klin A, Hannigen S, Dichtel LE, Volkmar F. Parental recognition of developmental problems in toddlers with autism spectrum disorders. J Autism Dev Disord. 2007;37:62–72. https://doi.org/10.1007/s1803-006-0330-8.
25. Siperstein R, Volkmar F. Brief report: parental reporting of regression in children with pervasive developmental disorders. J Autism Dev Disord. 2004;34:731–4. https://doi.org/10.1007/s10803-004-5294-y.
26. Davidovitch M, Glick L, Holtzman G, Tirosh E, Safir MP. Developmental regression in autism: maternal perception. J Autism Dev Disord. 2000;30:113–9. https://doi.org/10.1023/A:1005403421141.
27. Luyster R, Richler J, Risi S, Hsu WL, Dawson G, Bernier R, et al. Early regression in social communication in autism spectrum disorders: a CPEA Study. Dev Neuropsychol. 2005;27:311–36.
28. Avdi E, Griffin C, Brough S. Parents' constructions of professional knowledge, expertise and authority during assessment and diagnosis of their child for an autistic spectrum disorder. Br J Med Psychol. 2000;73(3):327–38. https://doi.org/10.1348/000711200160543.
29. Martínez-Pedraza FDL, Carter AS. Autism spectrum disorders in young children. Child Adolesc Psychiatr Clin N Am. 2009;18:645–63. https://doi.org/10.1016/j.chc.2009.02.002.
30. Sices L, Feudtner C, McLaughlin J, Drotar D, Williams M. How do primary care physicians manage children with possible developmental delays? A national survey with an experimental design. Pediatrics. 2004;113:274–82. https://doi.org/10.1542/peds.113.2.274.
31. Howlin P, Asgharian A. The diagnosis of autism and Asperger syndrome: findings from a survey of 770 families. Dev Med Child Neurol. 1999;41:834–9.
32. Mandell DS, Novak MM, Zubritsky CD. Factors associated with age of diagnosis among children with autism spectrum disorders. Pediatrics. 2005;116(6):1480–6. https://doi.org/10.1542/peds.2005-0185.
33. Soke GN, Maenner MJ, Christensen D, Kurzius-Spencer M, Schieve LA. Brief report: estimated prevalence of a community diagnosis of autism spectrum disorder by age 4 years in children from selected areas in the United States in 2010: evaluation of birth cohort effects. J Autism Dev Disord. 2017;47:1917–22. https://doi.org/10.1007/s10803-017-3094-4.
34. Howlin P, Alcock J, Burkin C. An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. Autism. 2005;9:533–49. https://doi.org/10.1177/1362361305057871.
35. Taylor JL, Seltzer MM. Employment and post-secondary educational activities for young adults with autism spectrum disorders. J Autism Dev Disord. 2011;41:566–74. https://doi.org/10.1007/s10803-010-1070-3.
36. Esbensen AJ, Seltzer MM, Krauss MW. Stability and change in health, functional abilities, and behavior problems among adults with and without Down syndrome. Am J Ment Retard. 2008;113:263–77. https://doi.org/10.1352/0895-8017(2008)113[263:SACIHF]2.0.CO;2.
37. Shea V, Mesibov GB. Adolescents and adults with autism. In: Volkmar FR, Paul R, Klin A, Cohen DJ, editors. Handbook of autism and pervasive developmental disorders. Third ed. Hoboken: John Wiley & Sons; 2005.
38. Hastings RP, Beck A. Practitioner review: stress intervention for parents of children with intellectual disabilities. J Child Psychol Psychiatry. 2004;45(8):1338–49. https://doi.org/10.1111/j.1469-7610.2004.00357.x.
39. Weiss JA, Cappadocia MC, MacMullin JA, Viecili M, Lunsky Y. The impact of child problem behaviors of children with ASD on parent mental health: the mediating role of acceptance and empowerment. Autism. 2012;16:261–74. https://doi.org/10.1177/1362361311422708.
40. Costa AP, Steffgen G, Ferring D. Contributors to well-being and stress in parents of children with autism spectrum disorder. Res Autism Spectr Disord. 2017;37:61–72. https://doi.org/10.1016/j.rasd.2017.01.007.
41. Rayan A, Ahmad M. Effectiveness of mindfulness-based intervention on perceived stress, anxiety, and depression among parents of children with autism spectrum disorder. Mindfulness. 2017;8:677–90. https://doi.org/10.1007/s12671-016-0595-8.
42. Blackledge JT, Hayes SC. Using acceptance and commitment training in the support of parents of children diagnosed with autism. Child Fam Behav Ther. 2006;28:1–8. https://doi.org/10.1300/J019v28n01_01.
43. Ekas NV, Timmons L, Pruitt M, Ghilain C, Alessandri M. The power of positivity: predictors of relationship satisfaction for parents of children with autism spectrum disorder. J Autism Dev Disord. 2015;45:1997–2007. https://doi.org/10.1007/s10803-015-2362-4.
44. Kabat-Zinn J. Mindfulness-based interventions in context: past, present, and future. Clin Psychol Sci Pract. 2003;10:144–56. https://doi.org/10.1093/clipsy.bpg016.
45. Lunsky Y, Hastings RP, Weiss JA, Palucka AM, Hutton S, White K. Comparative effects of mindfulness and support and information group interventions for parents of adults with autism spectrum disorder and other developmental disabilities. J Autism Dev Disord. 2017;47:1–11. https://doi.org/10.1007/s10803-017-3099-z.
46.•• Hartley SL, Schultz HM. Support needs of fathers and mothers of children and adolescents with autism spectrum disorder. J Autism Dev Disord. 2015;45:1636–48. https://doi.org/10.1007/s10803-014-2318-0. **Article provides insight on the needs of fathers of children with ASD, a group often hard to find in ASD literature. Demonstrates the overlap of support needs between both parents, as well as father specific needs.**
47. Hartley SL, Barker ET, Baker JK, Seltzer MM, Greenberg JS. Marital satisfaction and life circumstances of grown children with autism across 7 years. J Fam Psychol. 2012;26:688–707. https://doi.org/10.1037/a0029354.
48. Navot N, Jorgenson AG, Vander Stoep A, Toth K, Webb SJ. Family planning and family vision in mothers after diagnosis of a child with autism spectrum disorder. Autism. 2016;20:605–15. https://doi.org/10.1177/1362361315602134.
49. Hall HR, Neely-Barnes SL, Graff JC, Krcek TE, Roberts RJ, Hankins JS. Parental stress in families of children with a genetic

disorder/disability and the resiliency model of family stress, adjustment, and adaptation. Issues Compr Pediatr Nurs. 2012;35:24–44. https://doi.org/10.3109/01460862.2012.646479.

50. Santelli B, Turnbull AP, Marquis J, Lerner E. Statewide parent to parent programs: partners in early intervention. Infant Young Child. 2000;13:74–88.

51.• Benson PR. The longitudinal effects of network characteristics on the mental health of mothers of children with ASD: the mediating role of parent cognitions. J Autism Dev Disord. 2016;46:1699–715. https://doi.org/10.1007/s10803-016-2699-3. **Article investigates the different aspects of social networks that hinder or support maternal self-efficacy and perceived support.**

52. DaWalt LS, Greenberg JS, Mailick MR. Transitioning together: a multi-family group psychoeducation program for adolescents with ASD and their parents. J Autism Dev Disord. 2017;48:1–3. https://doi.org/10.1007/s10803-017-3307-x.

53.• Krakovich TM, McGrew JH, Yu Y, Ruble LA. Stress in parents of children with autism spectrum disorder: an exploration of demands and resources. J Autism Dev Disord. 2016;46:2042–53. https://doi.org/10.1007/s10803-016-2728-2. **Article examines a new intervention that supports parents through their child's transition to adulthood.**

54. Johnson NL, Simpson PM. Lack of father involvement in research on children with autism spectrum disorder: maternal parenting stress and family functioning. Issues Ment Health Nurs. 2013;34:220–8. https://doi.org/10.3109/01612840.2012.745177.

55. Da Paz NS, Wallander JL. Interventions that target improvements in mental health for parents of children with autism spectrum disorders: a narrative review. Clin Psychol Rev. 2017;51:1–14. https://doi.org/10.1016/j.cpr.2016.10.006.

56.• Shawler PM, Sullivan MA. Parental stress, discipline strategies, and child behavior problems in families with young children with autism spectrum disorders. Focus Autism Dev Dis. 2017;32:142–51. https://doi.org/10.1177/1088357615610114. **Article examines association between stress, discipline strategies, and child behavior problems. Impact of discipline strategies could especially important as a target for intervention that would help reduce stress and improve child's behavioral issues.**

57. Kuhlthau K, Payakachat N, Delahaye J, Hurson J, Pyne JM, Kovacs E, et al. Quality of life for parents of children with autism spectrum disorders. Res Autism Spect Dis. 2014;8:1339–50. https://doi.org/10.1016/j.rasd.2014.07.002.

58. Bronfenbrenner U. Toward an experimental ecology of human development. Am Psychol. 1977;7:513–31.